Commonwealth Neurotrauma Initiative Trust Fund

Meeting Minutes September 21, 2007 DRAFT

Members Present

Richard Bendall, Jr., MD Monelison Family Physician, Lynchburg Terry Glenn Department of Corrections, Richmond

Doug Harris, J.D. State Health Commissioner Designee, Richmond Gregory Helm, M.D., Ph.D. University of Virginia Medical Center, Charlottesville

Teresa Poole Lakeview Blue Ridge, Blacksburg

David Reid, Psy.D., Chair
Jim Rothrock
Comprehensive Health Systems, Fishersville
Department of Rehabilitative Services, Richmond

(*Ex-officio*)

Members Absent

Staff

Kristie Chamberlain Department of Rehabilitative Services, CNI Program

Administrator

Patti Goodall Department of Rehabilitative Services, Manager, BI/SCI

Services

Guests

Eric Messick Joint Legislative Audit Review Commission (JLARC)

Kelli Williams Virginia Commonwealth University (VCU)

David Gater, MD, Ph.D. McGuire Veterans Administration

The Commonwealth Neurotrauma Initiative (CNI) Advisory Board met for a regular quarterly business meeting in Conference Room 135 at 1606 Santa Rosa Drive in Richmond, Virginia. Dr. David Reid, Chair, convened the meeting at 10:08 a.m.

Public Comment Period

A public comment period was held. No public comment was taken.

Approval of June 1, 2007 Minutes

Dr. Bendall made a motion to approve the minutes with the noted change from staff on page 4 of the minutes, under "Future Meeting Dates"--the next meeting date indicated on the minutes should read December 7, not 8. Terry Glen seconded the motion; motion passed unanimously.

Approval of September 21, 2007 Agenda

Presentation from Kelli Williams, Research Fellow, Virginia Commonwealth University Dr. Juan Carlos Arango and Ms. Kelli Williams came to the Board during public comment at the June 1, 2007 Board meeting marketing a multidisciplinary conference on cultural / ethnic issues affecting the treatment, care, and access to services for individuals with TBI. The conference would be the first of its kind in the nation to feature leading experts from across the country to present data, share strategies, and promote translational research on minorities with brain injury. Virginia Commonwealth University is looking for donations upwards of \$50,000 to plan and organize a conference of this magnitude and asked CNI to contribute to the conference with a stipend to support it. After the June meeting, the Advisory Board asked Dr. Arango and Ms. Williams to come back in September and give a status report of financial donations and other progress made to date.

Ms. Williams presented the Board with information on planning accomplishments to date for the conference projected to occur in October/November 2008. Ms. Williams presented information on total expenses for the conference averaging about \$56,950. Total Revenue to date is at \$16,000, so monies needed are \$41,000. Partners to date are: The Henry Kesler Foundation, the Center for Capacity Building for Minorities with Disabilities Research, National Institute on Disability and Rehabilitation Research, Virginia Commonwealth University, and the Traumatic Brain Injury Model Systems National Data and Statistical Center. Ms. Williams commented that next immediate steps to seek support would be with: the American Congress of Rehabilitation Medicine, the Brain Injury Association of America, the International Brain Injury Association, and the American Psychological Association. The Board recommended a few other options for funding through NAACP and the Urban League etc. Discussion ensued among Ms. Williams and the Advisory Board. When asked in an ideal world how much money Ms. Williams would ask CNI to contribute, she said \$41,000, but in a realistic world she was asking CNI for \$25,000 towards the conference. The Board thanked Ms. Williams for her presentation and said that they would be in touch.

Discussion ensued re-the CNI Trust Fund's purpose and intent in the code of Virginia. The Board unanimously agreed that the funding stream of CNI is not large enough to fund individual requests for support conferences while still allowing it to maintain its original intent to fund grant initiatives. **Dr. Bendall made a motion not to fund the National Multidisciplinary Conference on Ethnicity, Culture and Brain Injury Rehabilitation proposed by Ms. Williams from Virginia Commonwealth University. Teresa Poole seconded. The motion passed unanimously.**

Presentation from David Gater, MD, Ph.D., McGuire Veterans Administration (affiliated with VCU).

Dr. David Gater from the McGuire Veterans Administration (affiliated with VCU) proposed an idea to the Board to fund a state-of-the-art lecture series that would bring in researchers from outside Virginia to speak at a monthly lecture series focused on traumatic brain injury and spinal cord injury research. Dr. Gater presented the Board with possible speakers and topics for the series. The speaker fees would be about \$1500/speaker or \$15,000/year. The audience for the

monthly lecture could be anyone from clinicians and investigators to consumers and families of consumers. Dr. Gater explained he worked on similar endeavors in Kentucky and Michigan. In Michigan, the Paralyzed Veterans of America funded the conference series.

Discussion ensued between the Board and Dr. Gater. The Board thanked Dr. Gater for his time and said that they would be in touch.

Discussion continued on the proposal from Dr. Gater exploring options of partnering the lecture series with the research colloquium tentatively scheduled for 2010 as well as options to offer the lecture series as a stand alone as Dr. Gater proposed. Though the Board recognized and appreciated Dr. Gater's efforts to expand educational research opportunities in the Commonwealth, they were in agreement that the funding stream for CNI is not large enough to fund individual requests for support of outside educational opportunities while still allowing it to continue to follow the original intent of the Fund. **Doug Harris made a motion not to fund the proposal for a lecture series on traumatic brain injury and spinal cord injury presented by Dr. David Gater from McGuire Veterans Administration. Terry Glenn seconded the motion. The motion passed unanimously. The Commissioner requested that staff inform Dr. Gater that there is a possibility that the Department of Rehabilitative Services may be able to fund the initiative and to contact Commissioner Rothrock to discuss the endeavor.**

Presentation from Eric Messick, Project Leader, Joint Legislative Audit and Review Commission on the *Brain Injury Services in Virginia Report*

The Board invited Eric Messick to the meeting to summarize the findings of the Joint Legislative Audit and Review Commission (JLARC) Report on *Brain Injury Services in Virginia* which was presented to the General Assembly in draft form on September 10 and the Joint Commission on Healthcare on September 19. Mr. Messick specifically focused on the findings that could potentially impact the intent of the CNI Trust Fund which was a suggestion that using the funds from the CNI Trust Fund would be one way of relieving the need for services for persons with severe neurobehavioral issues; currently unavailable in Virginia. According to the report, because the fund produces about \$1.4 million dollars in revenue annually, the annual proceeds deposited in the CNI grant fund could be used to treat an average of 8 persons per year (at a rate of \$172,000/person/year for neurobehavioral services).

Discussion ensued. The Board thanked Mr. Messick for his presentation but the Advisory Board immediately informed Mr. Messick that they do not concur with listing CNI funds as a possibility to alleviate neurobehavioral service needs in Virginia. The Advisory Board and staff believe in endorsing the original intent of the Commonwealth Neurotrauma Initiative (CNI) Trust Fund by allowing for grant opportunities to expand and enhance services for individuals with brain injury and spinal cord injury in Virginia along with expanding opportunities for grant research on the mechanisms and treatment of neurotrauma. Further, this Board also maintains that failing to endorse the original intent of the trust fund will not only adversely impact citizens who have already suffered neurotrauma, but thousands more who could benefit from the cutting edge research and intervention programs/services funded through the CNI Trust Fund.

The Advisory Board Chair, Dr. Reid, thanked Mr. Messick for his time and sound review. Dr. Reid responded that he will be drafting a letter on behalf of the Advisory Board in response to the report findings. The Commissioner also informed the Advisory Board that he is writing a

response document for Secretary Tavenner to give to the Joint Commission on Healthcare in response to all of the findings in the report including but not limited to the recommendation to use CNI Funds to alleviate neurobehavioral service cost.

Discussion Re Development of a Request for Proposal (RFP) for a small neurobehavioral pilot project to generate outcome data to drive later neurobehavioral funding decisions. Dr. Reid informed the Board of an emailed request he received from Paul Aravich, Ph.D., the Chair of the Virginia Brain Injury Council Neurobehavioral subcommittee. The Neurobehavioral Council subcommittee who has been working on a white paper to look at the need for neurobehavioral services in the Commonwealth. Dr. Aravich sent an email to Dr. Reid a few weeks before the meeting to request that the Board consider releasing an RFP focusing on generating outcome data to drive neurobehavioral funding decisions. This suggested RFP would be listed as a recommendation in the subcommittee's white paper. The Board discussed the request and opted to table this discussion until a later date to see if the proposed Medicaid Waiver is able to fund neurobehavioral services.

The Board Chair will contact Dr. Aravich to inform him of the status of his request.

Comments from the Commissioner of DRS

The JLARC report cited the Virginia Brain Injury Registry (reporting requirement for hospitals was enacted in 1984) as faulty. Currently, the hospitals must report by completing the reporting form or submitting data electronically, the name, age, place of residence and cause of injury within 30 days to the Department of Rehabilitative Services who then keys the data into the Virginia Brain Injury Registry. The JLARC report found that the Brain Injury Registry is not collecting comprehensive information about TBI Survivors and the information and referral process is not producing desired results. Data compatibility problems have prevented at least two Level I Trauma hospitals in Virginia from reporting. The Brain Injury Association of Virginia (BIAV) then sends outreach mailers to the individuals reported in the registry containing information on services available to the individuals with brain injury (or their families). The JLARC report found that fewer than 2% of outreach mailers result in direct contact for additional information.

As a result of JLARC finding the Registry faulty, the Commissioner reminded the Board of his authority passed in a budget amendment in 2004 to use unexpended grant dollars to fund new grant awards for research on traumatic brain and spinal cord injuries: "Notwithstanding any other law to the contrary, the Commissioner may reallocate up to \$500,000 from unexpended balances in the Commonwealth Neurotrauma Initiative Trust Fund to fund new grant awards for research on traumatic brain and spinal cord injuries". The Commissioner informed the Board that he will be using about \$80,000 under his authority to work with Brain Injury Association of Virginia (BIAV) on a solicited proposal. The proposal would research alternative funding and improved outreach options for best practices to contact individuals with brain injuries thereby providing information on services available to them in Virginia vs. the previously used registry to release information on brain injury services.

Chair's DRAFT Letter to Katie Couric

The Chair, Dr. Reid, explained to the Board that he had drafted a letter to Katie Couric noting Virginia's accomplishments with the Trust Fund encouraging her to help coordinate a Fund in

CNI Advisory Board DRAFT Meeting Minutes September 21, 2007 Page 4 of 5 every state. Dr. Reid informed the Board that about only 10 states address SCI with their trust funds. The reason for the letter is that Dr. Reid was hoping to get the word out about CNI and what other trust funds do. The board decided to table approval of sending the letter and discuss the item at the December meeting.

Financial Report

Kristie chamberlain, staff to the Advisory Board, provided a comprehensive overview of the CNI Trust Fund finances. Since its inception in 1998 through August 31, 2007, total revenue into the fund is \$11,708,307.46. The Trust Fund has actually awarded \$14,473,441.63 in grant awards, (this includes 379,998.57 on administrative services since July 2003). The Fund currently has an obligated balance of \$2,765,134.17 (revenue minus grant awards) with an available balance of \$1,263,430.14 (revenue minus expenditures). The current monthly average in fees and interest into the Trust Fund in Fiscal Year (FY) 2008 (began July 1, 2007) is \$108,331.75 per month.

FY'07 Annual Report to the Governor

Kristie Chamberlain, staff to the Advisory Board informed the Board of the annual report to the Governor (due October 1) that encompasses a financial overview of FY'07 (July 1, 2006-June 30, 2007) as well as aggregate data on operations (grant awards, carryover requests etc.). New this year to the report is a draft list of publications (scientific or qualitative) as well as presentations and success in securing federal grant dollars (such as National Institute of Health) using CNI research that has resulted due to CNI grant awards. The report goes to the Secretary of Health and Human Services, Marilyn Tavenner for approval first and then to the Governor and General Assembly once approved twelve days later. Staff will email the report out the Advisory Board once it is released to go to the Governor's office.

Future Meeting Dates

The next meeting date is Friday, December 7, 2007.

Dr. Reid, Chair adjourned the meeting at 1:18 p.m.